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Parent Focus

April 2005

After Graduation . . . Exciting Times Ahead!

by Tracy Allen, Home School Coordinator

Transitions are a part of everyone's life. It's a very exciting time when a child is transitioning from school to adulthood, but it can also be a stressful time. Parents of a student who is attending one of the State Schools should be aware of the options that are available after graduation. The student could become employed at a non-supported worksite, a local workshop or may choose to attend a day program.

Worksites/Workshops

In order for a person to be successful in these settings there are some necessary skills involved. Generally each worker must:

- Be able to take care of own toileting needs.
- Be able to feed self.
- Be clean and dress appropriately. (If grooming is an issue, this will be dealt with by the supervisor in a workshop.)
- Be able to get on and off the bus if using public transportation or transportation provided by the workshop. In most instances the bus staff will assist a person in a wheelchair on and off the bus.
- Be able to follow simple instructions and stay in the assigned work area.
- Have some counting skills. (This is not required for all work situations.)
- Follow rules and regulations set by the employer (e.g. no foul language, no running, no horseplay). (In the event there is a behavioral problem, most workshops will work with the individual as long as the person is not violent.)

Day Programs

When individuals attend a day program they are not being paid to perform a duty. Therefore, the criteria in a day program are different. Requirements vary depending on the agency providing the day program. Areas to be considered are:

- In most cases the individual does not have to be toilet trained.
- Staff will assist with feeding and toileting.
- Staff will assist individual on and off the bus or in and out of a car.
- Staff will try to deal with behavioral problems and help the individual overcome the problem.
- Staff will assist with grooming issues when necessary.

In most day programs, the service provided is driven by a habilitative outcome. This is usually some type of life skill or personal care skill the individual and others involved in their care have chosen to focus on in order for the individual to become more independent.

Parents should work with their child's teacher during the transition period to become familiar with the requirements of local day programs and workshops. Most agencies have a designated area they serve; this determines the availability of transportation provided to and from workshops and day programs.

To help the student prepare for transition to a possible worksite, or to a workshop or day program, skills can be worked on at home, as well as taught at school. If the students' parents and teacher have an idea of what the student would like to do after graduation, they can help the student work on skills and abilities relevant to a particular job or program. The transition period for the IEP program begins when the student attains 14 years or earlier if needed. In developing IEP goals, the team should focus on skills acquisition needed by the student in adult life.

Parents and teachers need to discuss the student's ability level and what skills need to be addressed in order for the student to be successful in the proposed environment. In short, IEP goals should be suitable and appropriate to the environment the student will transition into after graduation. ■

Visual Scheduling System

by Janelle Burch,
Supervisor for Instruction

An effective way to help your child learn the steps to become more independent in self-care skills is to set up a sequence of pictures (photographs or line drawings) to be followed to complete the steps of the task. This will provide a visual cue of how to begin the task, what to do next and will show when the task is finished.

To get started, choose a self-care skill that you would like for your child to complete more independently, such as brushing teeth. Keep it very simple in the beginning, no more than six or eight steps. You can add more steps as your child's independence increases. The beginning steps might be:

Steps for brushing teeth	Picture to use
Get needed materials	a container with the toothbrush, toothpaste, and a cup
Wet brush	a toothbrush being held under running water
Put paste on brush	a toothbrush with paste being squeezed onto it
Brush teeth	a toothbrush being placed in mouth*
Rinse mouth	water being taken from a cup
Spit in sink	a sink
Rinse brush	a toothbrush being held under running water
Put materials back in container	a container with the toothbrush, toothpaste, and a cup in their proper place

** (You can monitor this step in the beginning and later work towards more independence in brushing front, back, and sides thoroughly.)*

These pictures can be laminated for durability and attached by Velcro to a horizontal or vertical piece of posterboard or foamboard (also laminated). Hang or place the board in a location where it can be seen by your child during teeth-brushing. As each step is completed, remove the picture and drop it into a special receptacle — a decorative cup or envelope pocket. The pictures are reattached to the board later ready for another session.

This system can be individualized for children using colors, themes, or accessories appealing to their interests. Use a superhero toothbrush or flavored toothpaste. The container might have a picture of Spiderman. Make it fun and motivate them to be successful.

Some children have trouble processing verbal directions and can use the visual cues more easily. Some children learn more quickly with a combination of verbal and visual cues. Talk your child through each step and point to the relevant visual schedule step. A system such as this shows a clearly defined beginning and end and a structured sequence in between.

Try it! You can speed up the process when time is short in the morning and then let your child take longer to work on each step when you have more time available in the evening. The scheduling system is portable and can go with your child to another setting if necessary. ■

Parent Focus

April 2005

State Schools for
Severely Handicapped
P.O. Box 480
Jefferson City, MO 65102-0480

Gary Schroer, Superintendent



The Missouri Department of Elementary and Secondary Education complies with Title VII of the Civil Rights Act of 1964, the Civil Rights Act of 1991, Section 504 of the Rehabilitation Act of 1973 as amended, and the Americans With Disabilities Act. Services are provided without regard to race, color, national origin, sex, or physical or mental disability.

Information concerning other available resources, programs, etc., is not to be construed as an endorsement by State Schools for Severely Handicapped for any specific product, organization or philosophy.

Parent Survey

by Merv Blunt, Central Office

In order to provide the best educational services for your child, State Schools for Severely Handicapped (SSSH) will be mailing a Parent Survey during the month of May. This survey will need to be filled out and returned to your child's school. The survey will provide an opportunity for you to express your opinion about the SSSH program and how well your child's educational needs are being met.

We will use the information from the surveys to identify areas where State Schools are doing well and areas where we need to improve. After all the information has been collected, the results will be used to make future decisions about State Schools focus and educational priorities.

This survey is similar to the one you will receive in September or October from the Missouri School Improvement Section, Department of Elementary and Secondary Education, as they prepare for the first Missouri School Improvement Plan (MSIP) review of SSSH in spring 2006. ■

Promoting Independence in Your Child

by Claudia Rampley,
Central Office

State Schools for Severely Handicapped

"Beliefs"

1. All children can learn.
2. All learning can be measured.
3. Everyone has the right to be treated with dignity and respect.
4. Educators have the ability to influence community attitudes regarding people with disabilities.
5. All skills, teaching materials and instructional settings must be consistent with the student's chronological age and functional to the person outside of the school setting.
6. Everyone has something to communicate.
7. All behavior serves a purpose.
8. A person is more than his or her disability.
9. Parents and educators play a critical role in the lives of children.

Eating, dressing and hygiene can be daily challenges for children with special needs. By implementing some of the following modifications at home, you can encourage your child to develop more independence in self care activities.

Dressing

- Children with fine motor difficulty can be encouraged to dress and undress themselves with little or no assistance by using zip rings attached to zipper tabs, button aides which pull buttons through buttonholes and Velcro closures.
- Elastic shoelaces or Velcro closures can be fastened with one hand or with limited grasp.
- Select clothing with no fastenings. Use short and long-sleeved T-shirts; sweat shirts and pants; pants, skirts and shorts with elastic waists.

Eating and Drinking

- Your child may be more successful eating from scoop bowls or plates, or plates fitted with a food guard.
- To help your child grasp utensils, buy spoons and forks with built-up plastic handles, angled handles or weighted handles. You can use cylindrical foam to build up the handles of regular utensils.
- If your child has oral motor difficulty, encourage independence in drinking by using cups with cut outs, spouts and various built-up handles, or drinking with a flexible straw.
- Use non-slip mats under your child's bowls/plates, cups, etc., to prevent the items from slipping on the table.
- Place picture or word labels on kitchen cabinets to help your child find specific food items or eating utensils. These labels will also assist your child in returning items to their proper place.

Hygiene

- If your child has a limited grasp, let your child use a wash mitt for washing himself.
- Cylindrical foam padding can also be used to build up the size of the handle on a toothbrush, hairbrush or comb and make it easier to grasp.
- If your child has difficulty stopping a task, set a timer for a minute or two as your child brushes his teeth or hair. Tell your child that the task is completed when the timer sounds.
- To promote self-care, let your child keep his grooming supplies, such as hairbrush, comb, toothpaste and deodorant, in a small colorful plastic basket or caddy.
- Use sturdy bathmats and diagonal or horizontal grab bars in the bath or shower if your child needs added stability for transfer in and out of the tub or shower. For added stability and to aid in sitting and standing from the toilet, use a raised toilet seat.

By utilizing some of these items to assist your child, you can boost self-esteem, confidence and encourage independence in your child. ■

Resources

The following companies offer many of the adapted items mentioned in this article. For a catalog, contact:

- Flaghouse Special Populations, 601 FlagHouse Drive, Hasbrouck Heights, NJ 07604-3116. Call toll-free 1-800-793-7900.
www.FlagHouse.com
- Sammons Preston Rolyan, P.O. Box 5071, Bolingbrook, IL 60440-5071. Call toll-free 1-800-323-5547.
www.sammonsprestonrolyan.com

SAFETY FIRST!

Teaching your child safety and community signs

by Karen Wells, Supervisor for Instruction

ONE OF THE MOST IMPORTANT AND functional skills to teach individuals with severe disabilities is to be safe in all environments, including home, community and school settings. It is imperative that they learn to identify, understand and follow safety words, signs and directions. Although these skills are taught in the school and community settings by school staff, it is just as crucial that they are taught in the home and community settings by parents.

Each child should be taught those skills he/she needs to be safe in the home and community setting. Here are some of the skills relevant to many SSSH students:

- Identify street signs and lights for pedestrians — STOP, DON'T WALK.
- Do not go into or cross the street when cars are coming.
- Identify signs found in your local neighborhood.
- Identify local restaurants and stores visited often by you and your child.
- Identify the correct restroom in public places.
- Identify household and community signs/symbols — POISON, FLAMMABLE, BEWARE OF DOG, DANGER – KEEP OUT, DO NOT ENTER, EXIT.
- Use household appliances safely.

As parents, you can assist your child in learning safety words, signs, symbols and rules through a variety of activities taught in the home and at community sites. Many activities can be participated in while following your daily routine in the home and community settings and do not require much, if any, additional planning or preparation.

Just as the specific skills you teach your child will vary depending on his/her needs, the techniques and methods used in teaching need to match his/her learning style.

- When out walking with your child, focus on the different safety signs. Take time to point out the signs and model the type of behavior that each sign represents. Stop at a stop sign or wait for the light to change before walking across the street, or have your child model for you the appropriate action for each sign.

- When out in the community, be a good role model by walking on footpaths and don't walk in the road unless crossing the street.
- Teach your child to stop, look to the right, look to the left, look to the right again and walk straight across the road — *never run!*
- Obtain restroom signs, either signs with words and/or words and symbols, from a local department or hardware store. Place one sign at a time on the door of your restroom at home. Discuss with your child if he/she should enter the bathroom at that time, dependent upon the sign on the door and gender of the child.
- When visiting local businesses, locate the restrooms and identify the appropriate restroom for your child's use. Repeat this activity as often as possible until your child selects the correct restroom on a consistent basis.
- As a preventative measure, keep all poisons up and away from disabled children, from very young to adult age. As an additional measure, paint a red X and/or place red stickers on all poisonous or dangerous household or garden products, and teach your child that the red "X" or red sticker means to stay away and don't touch.
- If your child is learning how to use simple household appliances, teach step by step how to use the appliance properly. Photos or line drawings of the steps to follow when using the appliance would be beneficial in teaching this skill and for your child to follow and refer to in the future. (Use the method described in Visual Scheduling on page 2.)
- You can purchase storybooks, games, and picture or word flash cards that practice survival, safety and community skills.

In addition to these games and activities, discuss with your child's teacher possible activities to use in teaching these skills. Your child's teacher is a valuable resource in determining the appropriate methods and learning activities to use in teaching new skills to your child. Through working as a team, your child is sure to be successful and safe in all environments! ■

Health and Personal Care Supplies

by Chokaio Benton, Becky Brozovich and Susan Cato, Home School Coordinators

Medicaid will pay for diapers for children over two years of age through age 21 where needed due to medical conditions and/or developmental delays. The procedure for obtaining diapers or pull-up training pants* is similar for all service providers.

1. Contact your primary care physician and schedule an appointment to discuss the need to obtain diapers and/or pull-ups service.
2. The primary care physician will contact your supply company to provide the prescription. The prescription needs to state the number of diapers needed, brand and size. Medicaid will pay for 186 diapers per month unless the child's doctor provides a medical necessity letter asking for a greater number. The prescription must also state that the child is incontinent due to a specific disability and is expected to remain so based on the disability.
3. The child's Medicaid card and details of any other insurance information are provided to the supply company by the physician or family member.
4. The supply company will contact the insurance provider to submit a Letter of Medical Necessity (which is completed by the primary care physician.)
5. Funding approvals or denials take from two to six weeks.
6. Once approval is received, diapers and/or pull-ups* can be supplied. Depending on the service provider, they can be shipped direct to your home or you can pick them up from the supplier.

** Currently a number of service providers are not offering pull-ups due to cost. If these are needed, the family may have to call several providers.*

The most helpful service providers will often complete the Medicaid forms for the families, as well as sending them to the physician for their portion to be completed. Home health care companies are helpful with this process because they are used to working with Medicaid and other programs for obtaining prior approval. They also see you as a potential customer for other medical equipment and they want to keep your business.

When looking for a service provider, ask whether they accept Medicaid. Will they help with the forms for Medicaid approval? Will they deliver or will you need to pick up at their store? You want a service provider that is helpful and knowledgeable with the process.

Diaper and Pull-Ups Providers	Delivery area (free shipping)
HDIS 1-800-269-4663, www.hdis.com	Anywhere in Missouri Straight Medicaid accepted.
Home Medical Supply 1-573-686-5510	Anywhere in Missouri Straight Medicaid accepted.
Care Med Equipment 1-800-203-8432	Anywhere in Missouri Straight Medicaid and private insurance. Does not accept MC+.
BJC Home Health Care 1-314-953-2000	St. Louis only Straight Medicaid and private insurance.
Edge Park Surgical (Ohio) 1-800-321-0591	Anywhere in Missouri. Does not accept straight Medicaid. Does accept Family Health Partners and First Guard Medicaid managed care plans and private insurance.

Home school coordinators may be able to help you with service providers in your area.

People over the age of 21 must meet the criteria for Medicaid Exception, which involves completing recertification paperwork similar to the process above.

If your child is not eligible for Medicaid or the Exception, you may want to contact your Regional Center for the Developmentally Disabled and ask about the Family Directed Support Program. At this time funding is based on prioritizing need. However, families are encouraged to apply for the services.

Families with private insurance will need to check whether or not diapers and pull ups are covered. If families are denied coverage when they believe it should have been provided, they can use advocacy groups to assist in obtaining the coverage. REACH for Kids will advocate for families in the greater Kansas City area and is willing to provide general information to parents in other areas. Contact information: (816) 931-8687 or www.reachforkids.org/. ■

Guardianship Questions

by Stephanie Brooks,
Central Office

RESOURCES

★ Missouri Protection and Advocacy Services
925 South Country Club Drive
Jefferson City, MO 65109
1-800-392-8667
www.moadvocacy.org

This organization offers a *Guardianship and Conservatorship Manual* that can be downloaded from their Web site or a copy may be obtained by writing or calling the office above.

To obtain a referral to an attorney:

★ Missouri Bar Law Referral Service
1-573-636-3635
www.mobar.org/lpmonline/referral

Call this number to obtain a referral to an attorney in your area. Referrals are not given for St. Louis, Kansas City or Springfield. For referrals in these areas, contact the local bar associations:
St. Louis (314) 621-6681
Kansas City (816) 221-9472
Springfield (417) 831-2783

If you believe you may qualify for free legal representation, contact:

★ Missouri Legal Aid Offices
www.mobar.org/legalser/offices

Western Missouri . . (816) 474-6750
Eastern Missouri . . 1-800-444-0514
 (314) 534-4200
Southern Missouri . 1-800-444-4863
 (417) 862-0356
Columbia 1-800-568-4931
 (573) 442-0116

In Missouri, the law states that when people reach the age of 18, they are recognized as legal adults capable of making decisions which affect their lives. In practice, the students attending State Schools for Severely Handicapped (SSSH) cannot make all, or possibly any, decisions about their care. This is why the question of guardianship is raised with parents by the IEP team or the home school coordinator.

Many parents assume they will continue to care for their child as they did when the child was younger. The parents are surprised or upset to hear that their child is now a legal adult and they might be questioned about making decisions related to medical, legal or financial issues on behalf of their child.

Each family must make its own decision on whether to apply for guardianship for their developmentally disabled child. Some families are prompted to do so if situation like these arise:

- The family is challenged by medical facilities, financial institutions and other organizations when consenting to or making decisions for their child.
- The child inherits property.
- Care of the child has passed to a family member other than the parents and it will be easier for this person (e.g., grandparent or sibling) to be named as guardian.

What is the difference between a guardian and a conservator?

Guardians and conservators are granted different powers by the court. A **guardian** makes decisions regarding daily care, employment, education, legal and health matters for a person who is incapacitated. The guardian should also advocate for that person's needs. The guardian is not responsible for paying for the care of the dependent adult and may obtain support from county and state sources if the person who is incapacitated lacks sufficient funds or assets to cover needed costs. A **conservator** is appointed to oversee the financial affairs of the person who is incapacitated, and may manage financial accounts and buy and sell property.

The court can appoint more than one person to act as a co-guardian or co-conservator. An appointee may be both guardian and conservator.

Who may serve as a guardian or conservator?

In most cases close relatives, such as parents and adult siblings, make the best guardians or conservators since they know the needs of the person who is incapacitated and this appointment is routinely approved by the courts. Other individuals or organizations may apply if no close relative is able or willing to serve.

Some people and agencies cannot be appointed as guardians or conservators (e.g., employees of public agencies and employees of facilities that care for individuals.) All guardians must be over the age of 18.

How to apply for guardianship and/or conservatorship?

Parents should approach their family attorney for assistance or ask to be referred to an attorney who specializes in these filings. Case managers at the Regional Centers or home school coordinators may be able to refer you to local attorneys who will complete the work pro bono or at a reduced cost for families who need this. The Public Administrator in your county may be helpful. ■

"Pennies for Pony Bird" Campaign

by Nancy Simpson, Home School Coordinator

During the month of March, Mapaville State School students, families, and staff participated in the "Pennies for Pony Bird" campaign. Pony Bird is a residential home for severely handicapped children and adults. Funds raised will be used to benefit Camp Pony Bird.

The top classroom was Alecia Glore with a total collection of \$166.35. Alecia's classroom will celebrate being the top collector by having an ice cream party at school. The other classrooms and amounts collected were: Karen Shepherd (\$140.95), Barb Poposky (\$99.73), Brenda Habsieger (\$90.63), Debbie Sanderson (\$36.54), and John Bevel (\$29.33).

Sara Sucharski, Director of Development at Pony Bird, met at Mapaville State School on Thursday, March 31, 2005, to collect the grand total of \$563.53. A big **thank you** to all the students, families, and staff who made this project a success. ■

PARENT RESOURCES

► Day Camps and Activities

The Recreation Council of Greater St. Louis (Serving St. Louis City, St. Louis County and St. Charles, MO)

Call (314) 726-6044 to obtain a copy of their *Summer Opportunities Guide*. Visit their Web site at www.stlouis.missouri.org/reccouncil. This includes details on day camps and summer activities for developmentally disabled children and teens.

Easter Seals (5027 Northrup Avenue, St. Louis, MO)

For details, call (314) 664-5025, Ext. 115. Day program is available 7:30 a.m.-6:00 p.m. from the last week in June until Labor Day. Students can attend full-time or afternoons only after summer school. Some funding is available.

Rainbow Center (900 NW Woods Chapel Rd., Blue Springs, MO)

For detailed information, call (816) 229-3869 weekdays between 3-4:30 p.m.

Full-day camp: 9:00 a.m.-3:30 p.m. • \$130 per week

Ages 13-Adult	June 4-8
Ages 5-12	June 11-15

Half-day camp: Noon-3:30 p.m. • \$130 for two weeks

Ages 13-Adult	June 18-29 and July 23-August 3
Ages 5-12	July 9-20
Ages 5-12	August 6-10 (one week only, \$65)

Concerned Care, Inc. (320 Armour Road, Suite 101, North Kansas City, MO)

For details, call John Whalen at (816) 474-3026. Camp is held June 25-July 25, 8:00 a.m.-4:00 p.m. (M-F) Ages 7-16, \$150/summer. For people with developmental disabilities.

Camps for Kids (1080 Washington, Kansas City, MO)

Call Zee Peters at (816) 559-4622. Visit their Web site at www.campsforkids.org. Provides scholarships to special needs children attending day or specialty camps and may be able to refer parents in other cities to available programs.

For families living in other areas, check with your home school coordinator or school building administrator for any available summer programs or activities. Details of residential summer camps were included in the December 2004 issue of *Parent Focus*.

► Directory of Resources for Missourians with Disabilities

The Governor's Council on Disability has recently updated this manual, which contains an extensive list of resources throughout Missouri. Obtain a copy by writing to: Truman State Office Building, 301 West High Street, Room 250-A, P.O. Box 1668, Jefferson City, MO 65102-1668. Phone: 1-800-877-8249.

► Calendar of Events

Families Together, Inc. (Kansas Parent Training and Information Center) • May 14, 2005

8:30 a.m.-2:30 p.m. • "Planning for the Real World When Your Child Has a Disability"
Coalition for Independence, 4911 State Avenue, Kansas City, Kansas. Register by calling (913) 287-1970. For more details, go to www.familiestogetherinc.org. Focus will be on transition and independence. *This is a free mini-conference.*

"Autism Symposium" • May 19-21, 2005 • Tan-Tar-A, Osage Beach, MO

Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. For more details call 573-751-9687 or 800-364-9687. The workshop is helpful for parents as well as professionals in the field.

MPACT Training for Parents • May 21, 2005

9:00 a.m.-Noon • "Special Education Law"

1:00-4:00 p.m. • "Understanding the IEP Process"

Both trainings will be held at the Western Missouri Medical Center (Classroom #1), 403 Burkhardt Road, Warrensburg, Missouri.

MPACT Training for Parents • June 13, 2005

9:00 a.m.-3:00 p.m. • "IDEA Boot Camp" (includes Special Education Law, the IEP Process and Problem Solving Strategies)

St. Louis Regional Center, 3101 Chouteau, St. Louis, Missouri. For more details call 1-800-743-7634 or visit their Web site at: www.highres.ptimpact.com. ■

2005-2006 SSSH School Calendar

► School Session Days

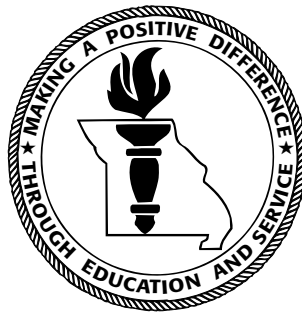
August 29	School Opening Day
September 5	Labor Day Recess
October 10	Columbus Day Recess
October 20-21	Workday and Inservice
November 11	First Quarter Report of Progress (Parent/Teacher Meetings)
November 24-25	Thanksgiving Recess
December 23-January 2	Winter Holiday Recess
January 3	Classes Resume
January 16	Martin Luther King, Jr. Day Recess
January 20	Second Quarter Report of Progress to Parents
February 13	Lincoln's Birthday Recess
February 20	Washington's Birthday Recess
March 31	Third Quarter Report of Progress (Parent/Teacher Meetings)
April 13-19	Spring Break
April 20	Classes Resume
May 8	Truman's Birthday Recess
May 29	Memorial Day Recess
May 30	Classes Resume
June 9*	School Closing Day
June 12	Fourth Quarter Report of Progress to Parents

**Closing date adjusted as needed to make-up days lost due to inclement weather or other factors.*

NOTE: All listings above designated in bold are student non-attendance days.

► Make-Up Schedule

Add-on days beginning with June 12, 2006, and consecutive weekdays following, as needed.



STATE SCHOOLS FOR SEVERELY HANDICAPPED
Missouri Department of Elementary
and Secondary Education

• • •

Web site: dese.mo.gov/divspeced/stateschools/

NOTE: If you have items of interest for the *Parent Focus*, please call 573-751-0706 (Missouri Relay 800-735-2966) or forward them to: Stephanie Brooks, State Schools for Severely Handicapped, P.O. Box 480, Jefferson City, Missouri 65102-0480. E-mail: Stephanie.Brooks@dese.mo.gov